

The Pediatric Evaluation of Disability Inventory and Its Contributions to Brazilian Studies

O Inventário de Avaliação Pediátrica de Incapacidade e Suas Contribuições para Estudos Brasileiros

El Inventario de Evaluación Pediátrica de Discapacidad y Sus Contribuciones a los Estudios Brasileños

Meriele Sabrina de Souza¹; Patrícia Pinto Braga^{2*}

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ABSTRACT

Objective: The study's main purpose has been to analyze the Brazilian scientific productions that used the Pediatric Evaluation of Disability Inventory (PEDI) in investigations focused on children diagnosed with disabilities. **Methods:** It is an integrative literature review which was carried out from July to August 2017 in the following data sources: MEDLINE (PubMed), Virtual Health Library (VHL) and Web of Science, in English, Portuguese and Spanish languages. **Results:** The use of PEDI contributed to the identification of individual disabilities and the most impaired functions in children, providing data that allows the planning of interventions for parents, professionals, and caregivers. Furthermore, it has revealed the benefits of physical activities for functional performance, as well as the effects of the guidelines transmitted by health professionals to children with developmental disorders. **Conclusion:** PEDI has been proved to be relevant as it contributes with evidence to the evolution of the child with disabilities, identifies the commitments and allows the redirection of the actions of professionals and caregivers.

Descriptors: Disabled Children, Rehabilitation, Equipment And Supplies.

¹ Nursing Undergraduate Student at the *Universidade Federal de São João del Rei (UFSJ)*. *Universidade Federal de São João del Rei (UFSJ)*, Brazil.

² Nursing Graduate by the *Universidade Federal de Minas Gerais (UFMG)*, PhD in Nursing by the *UFMG*, Adjunct Professor of the Nursing Graduation Course at the *UFSJ*. *Universidade Federal de São João del Rei (UFSJ)*, Brazil.

RESUMO

Objetivo: Analisar as produções científicas brasileiras que utilizaram o Inventário de Avaliação Pediátrica de Incapacidade (PEDI) em estudos voltados para crianças diagnosticadas com deficiência. **Metodologia:** Trata-se de revisão integrativa da literatura, realizada entre julho e agosto de 2017 nas seguintes fontes: MEDLINE (PubMed), Biblioteca virtual em saúde (BVS) e Web of science nos idiomas inglês, português e espanhol. **Resultados:** A utilização do PEDI contribuiu para identificação de incapacidades individuais e das funções mais comprometidas em crianças, fornece dados que permitem o planejamento de intervenções para pais, profissionais e cuidadores. Além disso, permitiu revelar os benefícios das atividades físicas para o desempenho funcional assim como os efeitos das orientações realizadas por profissionais de saúde para crianças com desvios de desenvolvimento. **Conclusão:** O PEDI têm-se mostrado relevante por contribuir com evidências sobre a evolução da criança com incapacidades, identificar os comprometimentos e permitir redirecionamento das ações de profissionais e cuidadores.

Descritores: Crianças com Deficiência, Reabilitação e Equipamentos e Provisões.

RESUMEN

Objetivo: Analizar las producciones científicas brasileñas que utilizaron el Inventario de Evaluación Pediátrica de Discapacidad en estudios centrados en niños diagnosticados con discapacidad. **Método:** Se trata de una revisión integradora de la literatura, efectuada entre julio y agosto de 2017 en las siguientes fuentes: MEDLINE (PubMed), Biblioteca Virtual en Salud (BVS) y Web of Science en los idiomas inglés, portugués y español. **Resultados:** La utilización del PEDI contribuyó a la identificación de discapacidades individuales y de las funciones más comprometidas en niños, suministra datos que permiten la planificación de intervenciones redireccionando las acciones de padres, profesionales y cuidadores, además de haber permitido revelar los beneficios de las actividades físicas para el desempeño funcional, así como los efectos de las orientaciones transmitidas por profesionales de salud para niños con desviaciones de desarrollo. **Conclusión:** El PEDI se ha mostrado relevante por contribuir con evidencias sobre la evolución del niño con discapacidades, identificar los compromisos y permitir redirección de las acciones de profesionales y cuidadores.

Descriptores: Niños con Discapacidad, Rehabilitación y Equipos y Suministros.

INTRODUCTION

ious diseases and consequently the survival of newborns with different congenital or perinatal problems has been identified. As a result, research points to the increase in the group of children with complex chronic conditions, which require continued, specialized and differentiated attention.¹⁻⁴

Chronic conditions in childhood can be defined as those that have a biological, psychological or cognitive basis that last or have the potential to last for at least one year, and have consequences such as: limitation of function, activities and social role; drug addiction, special diet, medical technology and assistive device; personal care and health and educational service needs beyond the usual for the child's age.⁵

Currently, the chronic condition in the Brazilian popu-

lation is a major health problem, accounting for 72% of the death causes of the population in different age groups and are responsible for 60% of all disease burden in the world. By 2020, they will account for 80% of the disease burden in developing countries.⁶ In Brazil, there is no consistent data on chronic childhood conditions. Adequate information on the characteristics, dependency, and description of the demands for rehabilitation care of this specific population is lacking. This makes it difficult to plan actions and organize health care services concerning comprehensive child-care in Brazil.²

Usually, the etiology for these conditions is multifactorial and the child with a complex chronic condition may have an uncertain, long-term prognosis and even lifelong permanent functional disabilities.⁶

Among the complex chronic diseases in the infant period, we highlight in this research the deviations in the development and the impairments. There is no consensus in the literature on the classification of disabilities, however, some guidelines need to be adopted when it comes to scientific studies to favor the production of consistent results. In this perspective, this research adopts the orientation of the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO), as it allows an analysis of health and disability in a broader context considering the social and environmental aspects. ICF considers that the functionality and disability of individuals are also determined by the environmental context in which they live. The ICF represents a paradigm shift in thinking and working on impairment and disability, and is an important instrument for assessing living conditions and promoting social inclusion policies.⁷

Children with disabilities require resolute care by health professionals because of the demands for care and health needs that they present, and it is relevant to consider that there is a need for improvements in the health care of this public, ensuring timely access to multi-professional care, assistive technologies, medicines, and therapy. Nevertheless, there are many current challenges for qualified care for disabled children and their families in the context of the Brazilian Unified Health System, such as difficulties in accessing orthotics, prostheses and mobility aids, lack of articulation between the different services and sectors that offer attention to the child, qualification and training for health professionals to have security in the care of this public and their family, among others.⁸

These challenges coupled with the lack of consistent data on disability in childhood make it difficult to plan actions aimed at this public in the field of health care. In this sense, adopting instruments and tests that reveal the profile of children with disabilities and their functional capacity may reveal the demands for care and health needs of this public and generate data on child disability in Brazil, as well as generate information and subsidies for schools, families, and professionals who accompany these children, contrib-

uting to the planning of interventions.

Considering the above, this investigation highlights the functional characterization instrument of children with different developmental disorders called Pediatric Evaluation of Disability Inventory (PEDI) developed by Haley et al. in 1992 and translated and adapted to the Brazilian context by Mancini in 2005. This instrument is intended to provide a detailed description of the caregiver's disabilities and care needs in daily activities.⁹

The development of PEDI emerged considering the scarcity of instruments that could reveal the abilities of children with disabilities and was based on the premise that functional performance should be analyzed considering the daily life of disabled children and their families. From this perspective, PEDI is not restricted to measuring children's limitations, but revealing their abilities, even in the face of intrinsic adversities to childhood disability.⁹ PEDI is an instrument that addresses part of the WHO proposal as ICF presupposes an analysis concerning disability. Considering the above mentioned, although there are other instruments in the Brazilian context, this study opted for the analysis of PEDI as an instrument for assessing children's functional performance.

The PEDI consists of a structured questionnaire that documents the functional profile of children between 6 months and 7 and a half years old. This functional profile informs about the child's ability performance (part I), the independence or amount of help provided by the caregiver (part II) and the changes in the physical home environment used in the child's daily routine (part III). Each part of the test provides information on the three function areas: self-care, mobility and social function.
9:18

It is a standardized questionnaire that can be administered in three different formats: direct questions to the caregiver; clinical judgment for professionals who are familiar with the child and who can report on their performance and direct observation of the child by the interviewer.⁹

This instrument has been adopted by researchers to evaluate several groups of children with different diseases and the results found have signaled about child deficiency in Brazil. From this perspective, the present investigation arose from the following question: What are the contributions and uses of PEDI in Brazilian studies with disabled children? Considering this perspective, this study aims to analyze the Brazilian scientific productions that used PEDI in studies aimed at children diagnosed with disabilities.

Highlighting the contributions, the different uses as well as the potentialities and limitations in the use of an instrument such as PEDI, which assess the functional performance of children with disabilities, may support research that wishes to use this instrument, as well as stud-

ies on disability in childhood. Allied to this, the results of this research reveal the different uses and contributions of PEDI in generating data on the functional performance of children with disabilities in the national context and such evidence is relevant considering the lack of information about the profile, the demands for care and health needs of children with disabilities in the national scenario.

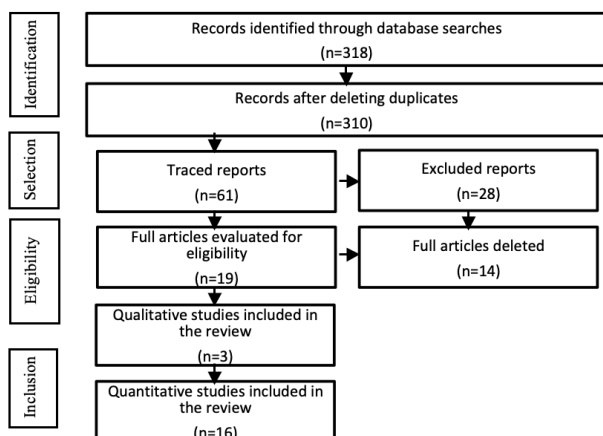
METHODS

This study is an integrative review of the literature, whose function is to synthesize results of previous studies on the proposed subject.¹⁰ Integrative reviews have the potential to show comprehensive understanding of specific issues and point out existing knowledge gaps. The steps followed in the elaboration of this review were: the establishment of the research question, literature search, data evaluation, analysis of included studies, interpretation of results and presentation of the review.¹¹

The guiding question of this study was "What are the contributions and uses of PEDI for Brazilian studies with disabled children?" The search was conducted between July and August 2017 from the following sources: MEDLINE (Medical Literature Analysis and Retrieval System Online), Virtual Health Library (VHL) and Web of Science. The time frame of the last 10 years was established for the inclusion of articles since PEDI was adapted to the Brazilian context in 2005. The terms used in the research were: Pediatric Evaluation of Disability Inventory, as well as its English and Brazilian versions. The articles were selected by two researchers, and the inclusion criteria were: original studies published in full that addressed, in the title or summary, the use of PEDI; studies published in Portuguese, English or Spanish. Works such as theses and dissertations, letters, editorials and publications in which the method was not clearly described were excluded.

For the selection of studies, the recommendations of Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA),¹² were followed, as shown in **Figure 1**. We initially found 318 records. Eight articles were excluded, since they were duplicated, 249 presented the title inconsistent with the research, 28 were excluded after reading the abstracts and 14 after reading in full for avoiding the guiding question. The final sample consisted of 19 articles.

Figure 1: Selection of included articles.



For the development of the study content analysis, a form was prepared by the authors with the following items: title, purpose, date of publication, study design, main results and conclusion. The results were analyzed and presented descriptively. Considering this is an integrative literature review, it was not necessary to request approval from the Ethics Committee for the study. The authors claim to have no conflict of interest.

RESULTS AND DISCUSSION

Among the 19 included articles 6 were published in the English language and the others in the Portuguese language, between 2009 and 2016. The distribution of the studies in the Brazilian states can be seen in **Figure 2**. About the type of study, the result was: 10 (ten) cross-sectional studies, 3 (three) case-control studies, 3 (three) refer to experimental research, 2 (two) are descriptive and 1 (one) case study; 16 used the quantitative approach and 3 the qualitative one. The main authors had training in physical therapy (n=10), medicine (n=5), occupational therapy (n=2) and physical education (n=2).

Figure 2: Distribution of publications in Brazilian states



The analysis of the 19 studies allows us to state that 18 studies used PEDI to evaluate children with disabilities. Among the children's disease diagnoses included in these studies following result was found: cerebral palsy (n=10), Down syndrome (n=1), Rett syndrome (n=1), meningoencephalocele (n=1), hemiplegia (n=1), low vision (n=1) and different types of disability (n=3). In contrast, one research used the instrument to evaluate preterm and term newborns.

Regarding the objective of the research, two studies used PEDI to assess school inclusion and the findings indicate that disability significantly compromises this process.¹³⁻⁴ In these studies, PEDI made it possible to identify individual disabilities contributing to the long-term monitoring of students,¹³ besides, pointing out social function as the most compromised area, enabling the planning of interventions for children and their families in the research setting.¹⁴

Analysis of the articles revealed that PEDI was used in research with children with Cerebral Palsy (CP) and occipital meningoencephalocele sequelae to analyze the benefits of aquatic physical activity^{15,6} and equine therapy.¹⁷ Using PEDI, before and after the researchers' intervention, these Studies have shown that physical activity, especially that developed in the aquatic environment, tends to improve social function, mobility, and manual skills; In addition to promoting greater independence and more effective social participation.^{15,6} It was also found that treatment by hippotherapy improved poise, functional activities and provided greater independence, as well as favoring self-care, interaction and communication with people.¹⁷

The results of this research reveal that PEDI was also used in studies to verify the effects of guidance to parents and caregivers regarding the functional abilities of chil-

dren with special needs, detecting that the orientations increased the performance of these children and their level of independence from the caregiver, proving to be a very important strategy for the family.^{19,20}

The analysis reveals that PEDI was used to analyze the influence of impaired postural control on functional performance. A study comparing the differences between typically developing children and CP found that children with CP have poorer performance in functional skills and mobility and need more caregiver assistance when compared to typically developing children. This knowledge can guide rehabilitation programs that improve children's insertion in their environment and show the real contribution of postural control to functionality.²¹

A study with children with Down syndrome showed that the collective activities in the format of workshops may be relevant to the functional development of these children. This evidence was built from the use of PEDI before and after the development of the workshops.²²

A study that included patients with Rett syndrome used PEDI to characterize the areas of greatest impairment in this child group and found that social function followed by self-care are the most compromised areas while mobility was less affected.²³

One of the experimental studies evaluated the effect of botulinum toxin A application on muscle spasticity and Range of Motion (ROM) in patients with CP. The results showed through PEDI that there was an improvement in ROM, influencing self-care and functional skills, but no decrease in caregiver assistance was observed.²⁴

The evaluation of the effects of Transcranial Direct-Current Stimulation (TDCS) applied on the primary motor cortex in children with CP showed that there was no significant improvement in the areas assessed by PEDI (self-care, mobility and social function) after the experiment.²⁵

Another study assessed, from the analysis of the PEDI results, changes in the functional use of the upper extremity in children undergoing the adapted Constraint-Induced Movement Therapy (CIMT) protocol, which consists of restricting the movement of the unaffected upper limb and providing intensive training in the affected limb. In this investigation, there was no significant difference in the results of the PEDI areas, since the children submitted to this treatment protocol had high scores from the beginning, but there was an improvement in the quantity and quality of the use of the affected upper extremity during the performance of functional activities.²⁶

The analysis of the articles allowed us to identify how

the stimuli present in the home environment influence the functional abilities of children with low vision, as well as the level of caregiver assistance in mobility. It was found from the PEDI results that there was no difference in functional skills, caregiver assistance and mobility of children with low vision when compared with children with normal vision, which may be justified by the small sample that comprised the study.²⁷

The results showed that using PEDI it was possible to investigate the relationship between family Socioeconomic Status (SES) and performance of children with CP, finding that children with low SES had less independence and more impaired functional skills.²⁸

Adopting PEDI, an investigation revealed the effect of follow-up with a speech therapist and physiotherapist and only with the physiotherapist of children with CP. It was found that there was no significant improvement in either area when comparing follow-up with one treatment and both. This result may be influenced by the small sample size and diversity of the disease.²⁹ Through PEDI it was also possible to analyze the level of dependence and need for care presented by individuals with CP. Showing that the areas that demand the most care are the social function followed by mobility.³⁰

The only study in which its sample was not composed of disabled children evaluated motor coordination, cognitive development and functional performance of preterm and full-term children. It was found that those born preterm have worse performance, fewer functional skills and need more assistance from their caregivers than their full-term peers, needing special attention.³¹

Only one study indicated as a limitation the language used in the instrument, as the family Socioeconomic Status and the caregiver's education may interfere with the ability to answer the questionnaire, influencing the result.²⁴

Figure 3 summarizes the results of this review by presenting the use of PEDI and its contributions.

Pediatric Evaluation of Disability Inventory	
USE	CONTRIBUTIONS OF RESULTS
<ul style="list-style-type: none"> Assess the effects of physical activity; Describe the disabilities that may hinder the school inclusion process; Relate socioeconomic status to functional performance; Check the effect of caregiver orientation; Evaluate the effects of botulinum toxin A application, Constraint- 	<ul style="list-style-type: none"> Provide information for intervention planning; Redirecting parent and caregiver actions; Identification of individual disabilities; Identification of the influence of Socioeconomic Status on functional performance; Highlight the Benefits of Physical

<p>Induced Movement Therapy and Transcranial Direct-Current Stimulation.</p> <ul style="list-style-type: none"> • Check the effects of physiotherapy and/or speech therapy; • Compare the development of preterm infants with those born at term; • Analyze the influence of the environment on children with low vision. 	<p>Activity;</p> <ul style="list-style-type: none"> • Direct orientation to parents and carers; • Benefits of applying botulinum toxin A; • Effectiveness of different types of therapies;
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Figure 3: PEDI Utilization and Contributions.

The analysis of the articles allows us to infer that the PEDI is an opportune instrument to contribute with evidence on the evolution of children with disabilities and helps to demonstrate the effectiveness of various types of therapy to increase the performance of children with disabilities. Besides, it provides evidence of improvements in problem solving, interaction with peers, object play, household chores, community functions, and interactive social games. for possibilities of interventions more directed to areas of greater commitment.¹³

As well as studies included in this investigation, other research states that physical activities have facilitated social inclusion. Moura et al. (2012), points out that they favor the participation of people with various types of impairment, enabling their insertion in the sports environment and, consequently, their social inclusion.³² According to Lehnhard et al. (2012), the practice of physical activities provides benefits for well-being and quality of life, besides testing the limits and potentials, can also prevent diseases secondary to disability, promote social integration and rehabilitation.³³

In consensus with the literature, from the use of PEDI, it was possible to identify the benefits of orientation to parents and caregivers. Rabelo and Melo (2016), affirm that a program with this purpose can properly direct the care that the family gives to people with disabilities and contribute to the rehabilitation process at home. Counseling is essential to provide adequate support for the child's treatment. Also, it has been considered an important factor in ensuring greater family participation in rehabilitation.³⁴

The result of the analysis of the present study revealed by PEDI the differences in the development of children with CP and typical development. Studies affirm that there is a significant variation in functionality within different levels of motor severity directly influencing mobility, self-care, and social function. Gross motor functions are related to activities of daily living, the higher the degree, the greater the impact on functional activities.³⁵

Taking into account the findings of the PEDI research

regarding the effects of botulinum toxin A, research on the subject has shown that its use in the management of spasticity in children with CP has been employed for over two decades, bringing benefits to this population. There is an improvement in range of motion, among other aspects, is considered an effective treatment.³⁶

In this review, it was evidenced that a study using PEDI identified that the Socioeconomic Status influences the performance of children with CP. In consensus with the literature, the study by Cury et al. (2013) states that mobility is directly related to the family socioeconomic status and the environment in which they live, directly impacting their mobility, especially at home.³⁷ Cultural and environmental conditions have effects on developmental domains, especially on cognitive and language performance.³⁸

Regarding the result of the more compromised areas found through PEDI related to caregiver assistance, other studies also affirm that the higher the functional disability, the greater the caregiver dependence, as it is related to the motor function that directly influences self-care and mobility. When functional skills are compromised the child requires more caregiver assistance.³⁵

According to what is reported in the literature, it was possible to identify the difference between the functional abilities of preterm and full-term children through PEDI. There are specific changes in the cognitive development of preterm infants. Viana et al. (2014) say that this impairment directly influences intelligence, however, several factors contribute to the future performance of these children.³⁹ The functional abilities of premature infants are lower when compared to the performance of full-term children. There are significant differences in gross and fine motor function, socialization and language.³⁸

Regarding the limitation of the questionnaire, studies that verify the validity of instruments state that educational and socioeconomic conditions have been identified as intervening in the responses, influencing the quality of information. Although, the questionnaires must have an appropriate language, according to the characteristics of the population to be studied.⁴⁰

CONCLUSIONS

This research allowed revealing from the analyzed articles the different and timely contributions of PEDI to research aimed at children with disabilities in Brazil. In addition to PEDI revealing data on child commitment and progress, it provides important information for interven-

tion planning.

We also concluded that investigations using PEDI showed the benefits of physical activity as well as the effectiveness of different types of therapies with children with disabilities and showed the relevance of guidance for caregivers and family members. This evidence contributes to the various professionals working with these children, highlighting individual needs and directing actions.

In this investigation it is believed that one of its limitations is the scarcity of Brazilian experimental studies using PEDI, which compromises generalizations and meta-analysis.

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***Corresponding Author:**

Patrícia Pinto Braga
Rua Sebastião Gonçalves Coelho, 400
Chanadour, Divinópolis, Minas Gerais, Brasil
E-mail address: patriciabragaufsj@gmail.com
Telephone number: +55 31 9 93532459
Zip Code: 35.501-296

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